



## EXPERIENCES OF PEOPLE LIVING WITH HIV IN SEEKING HIV HEALTH SERVICES DURING COVID-19 PANDEMIC IN DENPASAR

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### ABSTRACT

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People living with HIV (PLWH) need to maintain their health status by seeking HIV health services. However, HIV health services have been impacted by the Covid-19 pandemic and affected antiretroviral therapy (ART) for people living with HIV. This study aimed to explore the experiences of people living with HIV seeking HIV health services during the Covid-19 pandemic. This study used a qualitative research design with a descriptive phenomenological approach. Semi-structured interviews were used with eight participants with a purposive sampling technique. Thematic analysis was used for data analysis in this study. This study found three themes, namely barriers to access to HIV health services during the Covid-19 pandemic and motivation to access HIV health services as the second theme. The third theme is adapting HIV health services during the Covid-19 pandemic. PLWH has had challenges accessing HIV health services during the Covid-19 pandemic. However, they have the motivation to maintain their health status by following new policies during the new normal period during the Covid-19 Pandemic. Communication, information, and education related to Covid-19 and new policies for accessing HIV health services must be provided by HIV nurses. The goal of such provision is to maintain health status, prevent loss to follow-up ART, and improve the quality of life of PLWH.

#### Keywords:

Covid-19, Experience, Health services, People with HIV

### BACKGROUND

People living with HIV (PLWH) are susceptible to Covid-19 due to being immunocompromised. Immunocompromised causes a depletion of the Cluster of Differentiation 4 (CD4) in the blood, resulting in a reduced capacity of the immune system to defend against infection with the Covid-19 virus (Danwang et al., 2022). This will affect the health status of people living with HIV worldwide. In 2020 37.7 million people were living with HIV, and 1.5 mil-

lion new cases of HIV were found (UNAIDS, 2021). Indonesia is one of the countries with a relatively high number of cases. In 2020 it was confirmed that there were 50,617 new cases of HIV/AIDS in Indonesia, and 1,704 cases were found in the province of Bali (Ministry of Health of the Republic of Indonesia, 2021). It is feared that this number will continue to increase, and there is a risk of death for people living with HIV infected with Covid-19 if people living with HIV do not get correct information about health protocols through HIV health services amid the Covid-

19 pandemic (Bhaskaran et al., 2021). On the other hand, HIV health services are disrupted in terms of prevention, diagnosis, treatment, and outbreak control aspects of the HIV epidemic (Brown et al., 2021).

The Covid-19 pandemic has caused many programs to be unattainable, and access to HIV health services has decreased. The number of Voluntary Counseling and Testing (VCT) from January - March (quarter I) 2021 compared to the period October - December (quarter IV) 2020 was 846,785 to 810,846, 404 people stopped ART, and 2,729 people with HIV/AIDS lost to follow up (Ministry of Health of the Republic of Indonesia, 2021). Some of the things that were experienced by people living with HIV during the Covid-19 pandemic are as follows: 40.7% of people living with HIV were worried about running out of ARV drugs, 50.4% of people living with HIV felt they lacked support, 32.2% had difficulty trying to access treatment, and 33.9% of people with HIV avoided access health services (Pantelic et al., 2021; Sasono, 2021). Avoiding access to health services is inseparable from stigma in people living with HIV, and thus they choose to manage stigma independently (Raya & Nilmanat, 2021). HIV health services that are friendly and conform to the rules of the Covid-19 health protocol are what people with HIV are looking for.

People living with HIV depend highly on HIV health services to maintain their health status. Antiretroviral therapy (ART) is a way of survival for people living with HIV; a journal that refers to WHO guidelines states that ART is an essential need that should be a priority in HIV health services (Stover et al., 2021). One way to get ARV is by accessing HIV health services. The Health Belief Model (HBM) theory explains that several factors influence the behavior of accessing health services. The perception of a person who feels vulnerable to a certain disease will increase the severity of health problems, where the threat will slowly stimulate cues to action, and the perceived benefits would be greater than the accepted barriers; it increases preventive behavior in accessing health services (Berhimpong et al., 2020; Mckellar & Sillence, 2020). These factors help improve the quality of life of people living with HIV when they access HIV health services, such as getting ARV needs, monitoring, and care needed for people living with HIV (Jozani et al., 2019; Ofori, 2019). Accessing HIV health services during the Covid-19 pandemic benefits people living with HIV.

Dorward et al. (2021) explained that access to health services during the Covid-19 pandemic was hampered. HIV testing and initiation of ARVs in HIV

health services decreased by 50% at the beginning of the Covid-19 lockdown (Dorward et al., 2021). Still, the study has not emphasized the perspective of PLWH when accessing HIV health services. Other literature studies showed that there is still a lack of research focusing on people living with HIV accessing HIV health services, especially in Indonesia (Luis et al., 2020; Mahalta et al., 2021; Sidjabat et al., 2021). Therefore, this study aims to explore the experiences of people living with HIV in seeking HIV health services during the Covid-19 pandemic in Denpasar City.

## METHODS

**Design and participants.** This study used a qualitative approach with descriptive phenomenological methods from April to May 2022. The selection of participants in this study used a purposive sampling technique based on inclusion and exclusion criteria. The inclusion criteria in this study were PLWH who were 18 years old or older, had access to HIV health services during the Covid-19 pandemic, and were willing to sign an informed consent after receiving an explanation of the study from the researcher. Data saturation became a reference in determining the number of participants, so eight were chosen for this study. The researcher used a semi-structured interview guide, which had been through due diligence by three experts from the nursing, qualitative, and HIV-AIDS fields.

**Research processes.** The researchers submitted a research application in Denpasar City from the National Unity and Political Agency of Denpasar City with the number: 070/222/BKBP. The permit was given to the Spirit Paramacitta Foundation in Denpasar, a non-governmental organization engaged in HIV-AIDS in Denpasar City. Participants received an explanation of the researcher's research approval and their roles in the research. Participants who agreed to participate were interviewed face-to-face using the SONY ICD-PX470 digital audio recorder.

**Data analysis and rigor.** Interview recordings went through the interview transcript stage in Indonesian after the interview process for each participant was completed. Data analysis was carried out using the theory of Colaizzi (1978) in Praveena and Sasikumar (2021). For the first stage, the researcher interviewed to dig deeper into the experience of PLWH in seeking HIV health services with bracketing techniques. In addition, the researcher also repeatedly read interview transcripts, memos analytics, and audiovisual recordings to elicit sensitivity to data. In the second stage, researchers looked

for significant statements from repeatedly reading interview transcripts with qualitative data processing applications. The third stage provides the meaning or code of each significant statement collected. In the fourth stage, researchers grouped codes into categories and themes. Researchers then consulted with supervisors experienced in qualitative and HIV in the fifth stage to get good theme results. In the last stage of the study, the researchers validated the theme results with member checking (Praveena & Sasikumar, 2021).

**Ethical considerations.** Ethical clearance permits were obtained through a full board review from the ethics committee of the medical faculty with the number: 605/UN14.2.2.VII.14/LT/2022. Participants received an explanation of the study before gathering informed consent for the interview. This study did not cause pain and loss. All participant data is stored in a locked folder, and the participants' names are changed with the participant code.

## RESULTS

**Characteristics of Participants.** The participants in this study were eight PLWHs aged 32 to 49 years. All participants access HIV health services in the city of Denpasar. The majority of participants were male. This research has five male and three female participants. The participants' educational background is high school (four people), junior high school (three people), and one with a Diploma 3 education. Most

of the participants are private workers (six people), and two are entrepreneurs. The characteristics of the participants can be seen in Table 1.

The results of this study are three main themes with nine categories which can be seen in Figure 1. The first theme is barriers to access to HIV health services. The participants said that the high price of viral load and CD4 tests resulted in economic difficulties for them, stated by several participants as follows:

"(the price) is quite high, the viral load and the CD4" (Participant 4).

"the economy is not good at this point..." (Participant 8).

Another obstacle participants felt when accessing HIV health services using BPJS (Social Security Administration Agency) is time. As stated by one of the participants as follows:

"the queue for BPJS users is long; there are so many people..." (Participant 6).

One participant expressed her desire to do a free viral load test to reduce the burden of medical costs, but there has yet to be a free viral load test. The participant's statement is as follows:

"...usually there is a free viral load test, but for now, there is no such thing (Viral load test). They said that

Table 1. Demographic Characteristic

Participant								
	P1	P2	P3	P4	P5	P6	P7	P8
<b>Type of Data</b>								
<b>Age (years)</b>	45	32	44	41	41	49	43	36
<b>Gender</b>	Male	Female	Female	Male	Male	Female	Male	Male
<b>Last Education</b>	Junior high school	Senior high school	Junior high school	Senior high school	Senior high school	Junior high school	Diploma 3	Senior high school
<b>Employment</b>	Entrepreneur	Private employee	Entrepreneur	Private employee	Private employee	Private employee	Private employee	Private employee

\*Note: Participants (P)

they would inform me later, I was informed in the past that there was a free test in March, but when I asked in March while doing my monthly check, the thing (Viral load test) was not available yet" (Participant 2).

The limited number of visits when one wants to access HIV health services was an obstacle that was stated by a participant as follows:

"...the number of patients was determined so that when they queued there (HIV health care facilities), most of the time it turned out that there was no more space and the health services could no longer be conducted because it was limited" (Participant 7).

Apart from this, the participants regretted that the interaction with the doctor was not too long, as stated by the following participant:

"...then we want to be with the doctor (counseling), but we cannot see the doctor for long, so we meet as necessary, and we are not allowed to say anything (health problem)" (Participant 7).

Participants also do not understand Covid-19 and are afraid of being stigmatized as positive for Covid-19, as stated by the participants as follows:

"...so I do not really understand about covid 19, I do not really like it" (Participant 2),  
 "... I am afraid because Covid-19 is anywhere if I do my regular check-up only to find out that I am Covid-19 positive" (Participant 2).  
 "...because it does not really affect HIV-positive people" (Participant 8).

The second theme in this study is the motivation for accessing HIV health services during the Covid-19 pandemic. The motivation is usually the support from people around the PLWH, such as family, friends, and friendly health workers that can strengthen PLWH mentality and help the participants to be enthusiastic about accessing HIV health services, as follows:

"...if it was not for a supportive family, we might have gone astray. actually" (Participant 4),  
 "at my place (a health care facility), the doctors are already accustomed to patients like us, so they are used to hanging out with transgender people and the like" (Participant 7),  
 "... psychosocial support is what we get..." (Partici-

pant 7),  
 "...it really guides us to seek treatment there (HIV health care facility)..." (Participant 8).

The free CD4 and viral load program motivate participants to access HIV health services, as stated by one participant as follows:

"I never paid for a CD4 viral load test. It is free..." (Participant 4).

The availability of free ARV drugs accompanied by enthusiasm to access ARV needs makes participants motivated; this can be seen from the following statements:

"the stock for my medicine is still safe" (Participant 5),  
 "...I want to stay healthy so I can be productive..." (Participant 7).  
 "...it raises our enthusiasm for treatment (access to HIV health services)" (Participant 8).

The third theme is adapting HIV health services during the Covid-19 pandemic, such as implementing health protocols: checking body temperature, wearing masks, washing hands, and maintaining distance. Participants conveyed their experiences as follows:

"...every time we access HIV health services, they will check our temperature..." (Participant 2),  
 "...we usually use multiple masks" (Participant 6),  
 "...and then we also wash our hands more often" (Participant 5),  
 "...and we have to keep our distance..." (Participant 7).

Concerning the operational adjustments to services delivered by participants, such as reducing crowds, shortening service hours, and giving two to three months of medication, the statements can be seen as follows:

"... so there are not too many people in one room, and it does not take too long as well..." (Participant 7)  
 "...like their working hours (HIV health care facilities) are usually much shorter now than before ..." (Participant 5)  
 "We are now given more drugs (ARVs). Now I will only need to restock once every three months" (Participant 8).

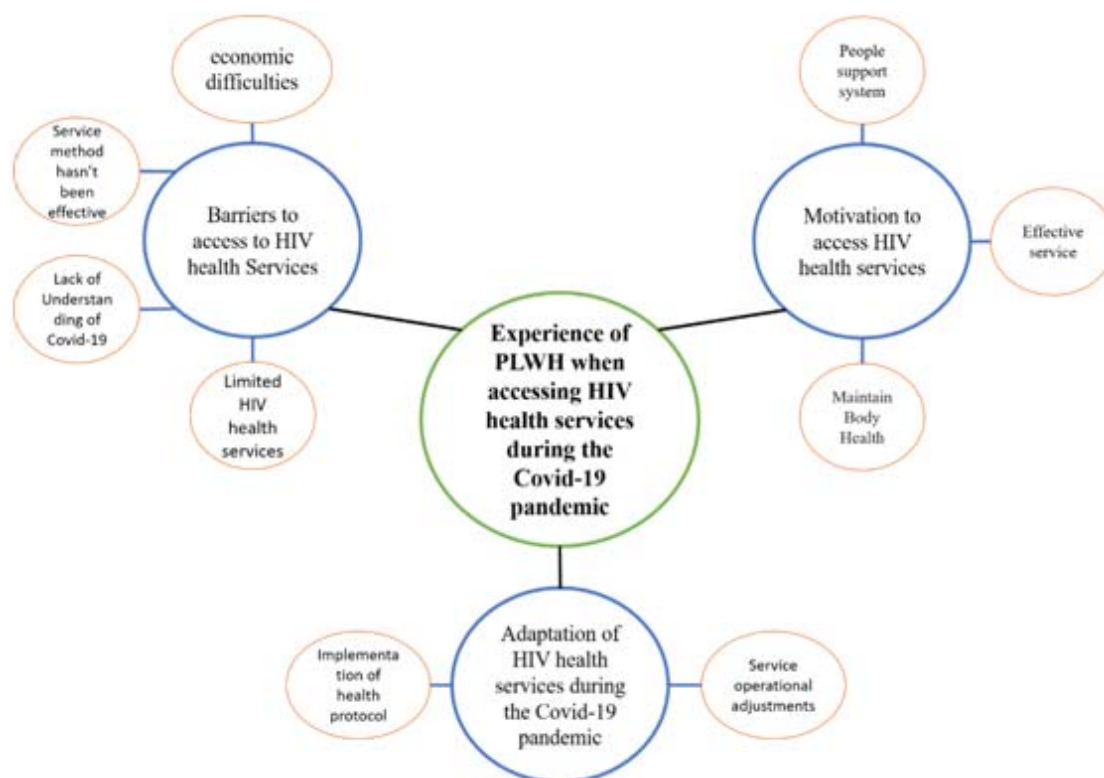


Figure 1. Thematic Map of the Experience of PLWH when Accessing HIV health services during the Covid-19 pandemic

## DISCUSSION

The results of this study showed that the reduced financial income of participants caused economic difficulties during the Covid-19 pandemic, which resulted in problems with treatment costs, especially when they wanted to access expensive viral load tests and CD4 tests. Other studies also stated that PLWHs experience a reduction in income and loss of work which impacts the anxiety of PLWHs being unable to pay for treatment (UNAIDS, 2022). The social distancing policy also plays a role as service sector jobs that depend on provider-customer interactions or involve many people are negatively impacted, such as reduced income and job losses (Sanchez et al., 2020). Research conducted in India suggested that ongoing financial constraints are highly correlated with difficulty accessing treatment (Singh et al., 2021). This is in line with what was felt by the participants of this study, most of whom worked in the service sector, such as traders and drivers, which impacted the difficulty of accessing HIV health services.

Participants shared their experiences when they wanted to access treatment using the Social Security Administration Agency (BPJS), which took longer. The average waiting time for outpatients is 68 minutes. Two reasons for the prolonged time consumption are patient consultation conducted in the

specialist doctor's room and the absence of standard operating procedures (SOPs) for standard waiting times (Wowor & Siswati, 2022). Waiting times longer than 30 minutes make patients accessing HIV health services less satisfied than patients who get HIV health services faster. Patient satisfaction will increase medication adherence, especially adherence to the advice given by doctors, and thus make people living with HIV return to access treatment for the long term (Gezahegn et al., 2021; Himakalasa et al., 2013). This is in line with what the study participants complained about regarding long waiting times caused by the different and time-consuming consultation times for each PLWH.

This study shows that fear of being stigmatized by Covid-19 and vulnerable to contracting other diseases makes some participants afraid to visit health facilities. People living with HIV are afraid of being exposed to Covid-19 due to negative issues if they are exposed to Covid-19, such as being afraid of the Covid-19 test. If the results are positive, the patients are required to be taken into isolation. In addition, the immunocompromised factor makes people living with HIV feel vulnerable to being exposed to Covid-19 and are afraid to visit HIV health services (Parikh et al., 2022). A similar study said that as many as 48% of respondents admitted that they were afraid to visit health facilities which could affect the continuity of

using ART (Karjadi et al., 2021). In line with the study, the participants were afraid of being tested positive for Covid-19. They had to undergo isolation in a special place, resulting in participants not wanting to visit HIV health services until their condition worsened.

Participants complained about going back home without getting adequate HIV health services due to restrictions on the number of visits, reduced visiting hours, and the implementation of social distancing. A study in line with this stated that inadequate health services were caused by reduced service hours, reduced interaction hours during counseling, and prioritizing social distancing to prevent Covid-19 (van Staden et al., 2022). The decrease in visits by PLWH to health services during the Covid-19 pandemic has harmed the reduction in care, support, and monitoring of the health status of PLWH during long-term ART (Ehrenkranz et al., 2019; van Staden et al., 2022). Participants in this study felt that they did not get time to express their health problems when accessing HIV health services and had to delay their desire to access HIV health services. The use of e-counseling is deemed appropriate to be advocated by HIV nurses and e-counseling providers from HIV health services to streamline consultations (Siradjuddin & Abdullah, 2019).

Some of the participants in this study said that their families were able to motivate them to access HIV health services. Family support can significantly increase the self-confidence of people living with HIV and encourage them always to access ART (Kumala et al., 2022). Research in Pakistan stated that families positively impact mentally strengthening people living with HIV in accessing health services. In contrast, the lack of support from family members will have an impact on people living with HIV in the form of feeling less important and uncomfortable and forgetting to take ARV drugs (Ahmed et al., 2022). Participants in this study also felt that the support they received strengthened them mentally always to access HIV health services, one of which was to access ARV drugs.

Almost all participants said they accessed HIV health services to meet their ARV drug needs. People living with HIV are very aware of the importance of continuing regular ARV treatment; poor adherence will decrease the immune system and CD4 cell count and allow resistance to ARVs (Kumala et al., 2022; Parikh et al., 2022). PLWH urgently needs access to ART during the Covid-19 pandemic to achieve an ideal viral load, reduce HIV-related morbidity and mortality, and prevent HIV transmission during the Covid-19 pandemic (Sun et al., 2021). In line with

this, other studies also stated that respondents who had received ART during the Covid-19 pandemic felt an improvement in physical health, body immunity, and appetite (Ahmed et al., 2022). Participants in this study also routinely take ARV drugs to maintain the body's immune system and stay productive.

Participants also felt very helpful and hoped that the free CD4 and viral load screening program could be routinely carried out for people with HIV. This is because the results of CD4 and viral load examinations can be a reference in the treatment sessions received and the follow-up that needs to be given to improve the quality of life of people living with HIV (Ehrenkranz et al., 2019). A viral load test is crucial to determine the clinical conditions experienced by people living with HIV. WHO recommends checking viral load after six months of initial antiretroviral therapy and at least once a year after starting ART (Ross et al., 2020; WHO, 2016). This is because the adjustment to the type of ARV obtained will then be adjusted to the results of the viral load and CD4 tests.

The stock of ARV drugs that are always available and the affordable cost of accessing ARVs allows participants to maintain their health amid the Covid-19 pandemic. In April 2020, the Indonesian government's policy allowed PLWH who did not have opportunistic symptoms and were in a stable condition to get ARV needs for up to three months; this shows the availability of enough ARV stocks in Indonesia (Karjadi et al., 2021). The low stock of ARV will cause doubts for people living with HIV to visit HIV health service centers (Chilot et al., 2022). Some participants in this study received ARV needs for two to three months because participants felt they were routinely accessing HIV health services; in addition, participants felt grateful because, at the HIV healthcare facilities they visited, ARV stocks were always available.

Health protocols in the form of hand washing and the implementation of social distancing in health services are quite strict as routine activities of participants before and during entry into HIV healthcare facilities. Under Indonesian government regulations, visitors to HIV health services must wash their hands with soap or hand sanitizer before entering healthcare facilities (Minister of Health of the Republic of Indonesia, 2020). This is because hands are the most easily transmitted medium for microorganisms from one person to another. Proper hand washing is required using the six-step method with a minimum of 20 seconds (Edmonds-Wilson et al., 2015; Wahyono, et al., 2021). Maintaining a distance of one to two meters is considered quite effective, followed by using surgi-

cal masks, N95 masks, and three-layer cloth masks to avoid splashing droplets on people with HIV (Mahalta et al., 2021; Minister of Health of the Republic of Indonesia, 2020). Nurses can provide education on good and correct hand washing and teach the importance and how to use masks correctly. This is because researchers still see that some people living with HIV are not using masks correctly; where two participants did not use masks, one participant used a surgical mask under the chin, and one used a buff mask.

Participants who accessed HIV health services said the services they received during the pandemic seemed to have accelerated. Participants were allowed to come to the HIV health service to take medicine only. This is also in line with what happened in the city of Padang. Participants only needed 15 minutes to access drugs, and a stock of two or three months of ARVs would be given to people living with HIV (Luis et al., 2020; Mahalta et al., 2021). Some countries have also implemented one to six months of ARV administration which aims to reduce the number of visits by PLWHs to HIV health services and increase the comfort of other PLWHs (Ahmed et al., 2022; Keene et al., 2020). Two of the eight participants in the study also said that they had two to three months of stock of the drug.

However, there is research that emphasizes the risk of administering ARVs for several months at a time as it causes fewer visits to HIV health services. It will be precarious as it disrupts awareness of people living with HIV to routinely take ARV drugs due to health workers' lack of support and active monitoring to ensure adherence to the care provided (van Staden et al., 2022). Thus, other studies suggested the need for strict eligibility criteria for PLWH to realize the benefits of extended dosing of ARVs (Keene et al., 2020). The objectives of providing education by HIV nurses to people living with HIV are to regularly visit HIV health services in order to improve the quality of life of people living with HIV. The study's limitations were that the interview process for one participant was conducted online according to the participant's request, so field observations were limited to the view of the participant's laptop/camera that the researchers could see.

## CONCLUSION

There are several points to be considered for PLWH in accessing HIV health services during the Covid-19 pandemic: barriers to accessing HIV health services, motivation to access HIV health services,

and adaptation of HIV health services during the Covid-19 pandemic. Other than that, nurses can provide education about the importance of health protocols for people living with HIV as one of the comorbid populations. Nurses in providing counseling can emphasize efforts to access HIV health services routinely. This research can be used as a basic reference in evaluating and developing HIV health service programs or policies for people living with HIV during the Covid-19 pandemic. Further researchers can develop the results of this study by looking at it from the point of view of healthcare providers in HIV health services in Indonesia.

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